Medicare for Children with Chronic Kidney Disease

This official government booklet has important information about the following:

- Finding out if your child is eligible for Medicare
- How to enroll your child in Medicare
- What Medicare covers
- How Medicare works with other types of health insurance

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Welcome

Finding out that your son or daughter has chronic kidney disease is difficult. Your child may have permanent kidney failure and need kidney dialysis or a kidney transplant. This is known as End-Stage Renal Disease. You will have many questions about his or her health condition and treatment options. You might also be concerned about paying for the health care costs that come with this disease.

The costs of kidney dialysis, kidney transplants, and other related services are expensive. These costs can create a financial hardship for any family caring for a child with kidney disease. This booklet will help you as a parent or caregiver understand how Medicare works to cover your child's health care costs. It doesn't have detailed information about kidney failure, dialysis treatments, and kidney transplants. To learn more about these things, talk to your child's health care team. The doctors, nurses, social workers, dieticians, and dialysis technicians that your child sees make up the health care team. They will help you understand your child's condition and find the best treatment options.

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The *Medicare for Children with Chronic Kidney Disease* booklet isn't a legal document. The official Medicare program provisions are contained in the relevant laws, regulations, and rulings.

The information in this booklet was correct when it was printed. Changes may occur after printing. For the most up-to-date version, look at www.medicare.gov on the web. Select "Publications." Or, call 1-800-MEDICARE (1-800-633-4227). A Customer Service Representative can tell you if you have the most up-to-date version. TTY (services for people who are deaf, hard of hearing, or have severe speech impairments) users should call 1-877-486-2048.

Medicare Basics

What is Medicare?

Medicare is a health insurance program for

- people of all ages with End-Stage Renal Disease,
- people age 65 or older, and
- people under age 65 with certain disabilities.

Medicare has two parts:

Medicare Part A (Hospital Insurance)

- **What it covers.** Medicare Part A helps cover care in a hospital, skilled nursing facility, and other services like kidney transplants.

- **What you pay.** Most people pay for Part A through their payroll taxes when they are working.

Medicare Part B (Medical Insurance)

- **What it covers.** Medicare Part B helps cover doctors' services, outpatient hospital care, and other medical services and supplies like dialysis treatment at home or in a facility.

- **What you pay.** Most people pay a monthly premium for Medicare Part B ($78.20 in 2005). Premiums can change every year.

Words in red are defined on pages 18–19.

You can find detailed information about Medicare-covered services and supplies by looking at www.medicare.gov on the web. Select "Your Medicare Coverage." To get the services that are covered by Medicare Part A and Part B, your child must meet certain conditions. To learn more about these conditions, you can call 1-800-MEDICARE (1-800-633-4227). TTY users should call 1-877-486-2048.

Medicare Eligibility

Is your child eligible for Medicare?

Your dependent child (see box below) is eligible for Medicare based on End-Stage Renal Disease if

1) **you (or your spouse) meet certain work requirements**—You or your spouse must have earned at least six credits within the last three years under Social Security, the Railroad Board, or as a Federal government employee. When you work and pay Social Security taxes, you get credits based on the amount you earn. In 2004, you get one credit for every $900 you earn. This amount can change every year. You can get up to four credits each year.

   Either you or your spouse must meet the work requirements. Both parents can't combine their credits to meet the requirements.

2) **he or she meets certain medical requirements**—Your child can only get Medicare if

   - he or she needs regular dialysis because his or her kidneys no longer work, or
   - he or she has had a kidney transplant.

Dependent child—usually an unmarried person under age 22 who is your

- child,
- legally adopted child,
- stepchild who is your stepchild for at least one year before you enroll them in Medicare, and
- a grandchild or stepgrandchild* (in some cases)

Someone who is age 22 or older is considered a dependent child if they have a disability that began before they turned age 22. Someone between age 22 and age 26 is a dependent child if they received at least one-half of their support from you or your spouse from the time they turned age 22.

* For more information about eligibility for your grandchild or stepgrandchild, call the Social Security Administration at 1-800-772-1213. TTY users should call 1-800-325-0778.

Enrolling in Medicare

Should I enroll my child in Medicare?

There are many reasons to enroll your child in Medicare based on End-Stage Renal Disease. You might consider Medicare if

- you or your spouse don't have private or employer group health plan insurance, or
- you have large out-of-pocket costs in your current policy.

Even if you currently have other health insurance coverage and low out-of-pocket costs, you still might want to consider Medicare. In the event that employment is lost or health benefits are reduced, Medicare can help protect your child's health care future.

Also, Medicare only covers immunosuppressive drugs if your child had Medicare Part A when he or she had their kidney transplant.

How do I enroll my child in Medicare?

You will need to enroll your child in both Medicare Part A and Part B in order for Medicare to cover certain dialysis and kidney transplant services. You can enroll your child in Medicare when he or she is diagnosed with End-Stage Renal Disease. To enroll

- visit your local Social Security office. The address and telephone number are in your local telephone book.
- talk to a member of your child's health care team for more information about how to enroll in Medicare.

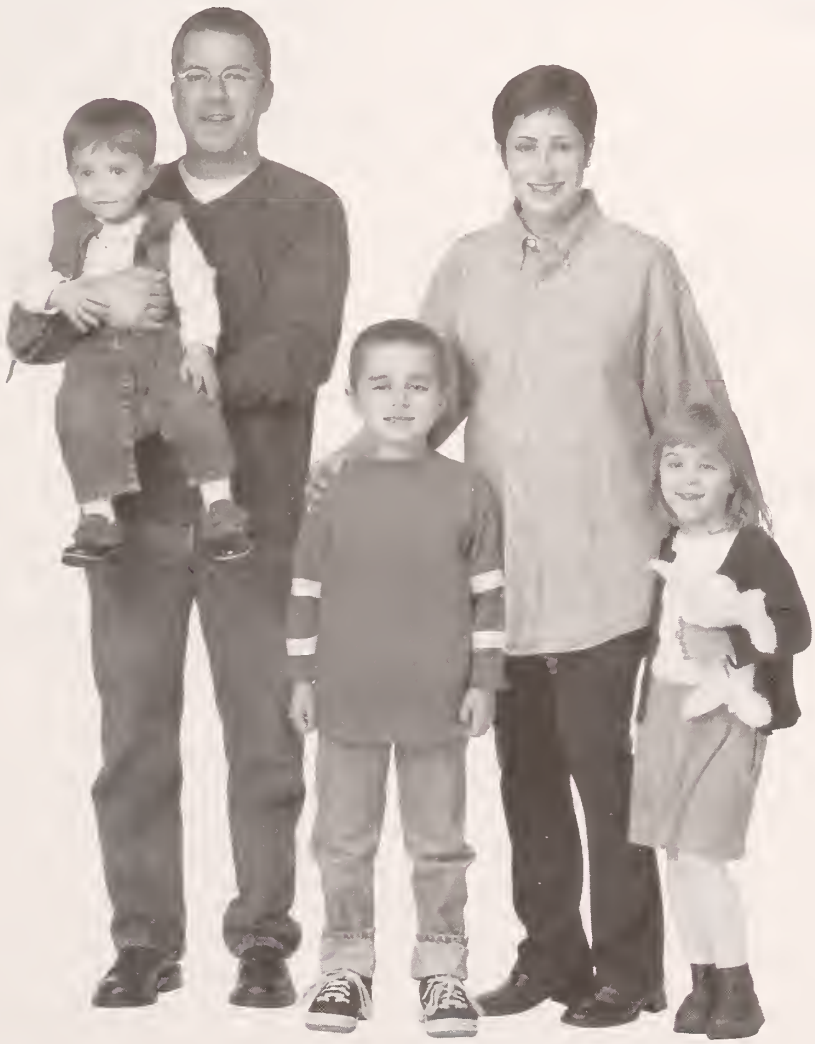
Words in red are defined on pages 18–19.

Enrolling in Medicare (continued)

What documents will I need to enroll my child?

Contact your local Social Security office or the Social Security Administration at 1-800-772-1213 to find out what documents you will need to enroll your child in Medicare. TTY users should call 1-800-325-0778. Some common documents you might be asked to bring include

- your child's birth certificate,
- your social security card, and
- CMS Form 2728 (End-Stage Renal Disease Medical Evidence Report Medicare Entitlement and/or Patient Registration). You will usually get this form from your child's doctor or dialysis unit.



When Medicare Coverage Begins and Ends

The start of Medicare coverage depends on the type of treatment your child gets.

When Medicare coverage for dialysis begins

If your child is on dialysis, Medicare coverage usually starts the fourth month of dialysis treatments. The first three months are called the "qualifying" or "waiting period." For example, if he or she starts dialysis treatments in July, Medicare coverage would start on October 1 of the same year.

Medicare coverage can start the first month of dialysis if your child

- starts home peritoneal dialysis or home hemodialysis, or
- was previously enrolled in Medicare because of End-Stage Renal Disease.

Course of Dialysis Treatment	1st Month July	2nd Month August	3rd Month September	4th Month October
Matthew starts dialysis in a dialysis facility in July.	<— Qualifying/waiting period.—>			Matthew's Medicare coverage begins.
Nicole starts dialysis at home in July.	Nicole's Medicare coverage begins.			
Sarah was previously enrolled in Medicare because of End-Stage Renal Disease and starts dialysis in July.	Sarah's Medicare coverage begins.			

When Medicare Coverage Begins and Ends (continued)

When Medicare coverage for kidney transplant begins

If your child has a kidney transplant, Medicare coverage usually starts the same month he or she has the transplant.

However, if your child is admitted to a Medicare-approved facility for health care services needed **before** the transplant and the transplant takes place within the following two months, Medicare coverage can begin the same month he or she is admitted. Also, if your child's transplant is delayed more than two months after being admitted to the hospital, Medicare coverage can begin two months before the transplant.

Course of Transplant Services	April	May	June	July
Christina is admitted to the hospital and has her transplant in April.	Christina's Medicare coverage begins (same month of transplant).			
Jayden is admitted to the hospital in April, but his transplant is delayed until June.	Jayden's Medicare coverage begins (same month he's admitted to hospital).		Jayden's transplant	
Maria is admitted to the hospital in April, but her transplant is delayed until July.		Maria's Medicare coverage begins (two months before transplant).		Maria's transplant

When Medicare Coverage Begins and Ends (continued)

When Medicare coverage ends

Your child's Medicare coverage will end

- 12 months after the month he or she stops dialysis treatments, or
- 36 months after the month he or she has a successful kidney transplant.

Your child's Medicare coverage won't end if

- he or she starts dialysis again within 12 months after dialysis stops,
- he or she gets a kidney transplant within 12 months after dialysis stops,
- he or she starts dialysis within 36 months after a transplant, or
- he or she gets another kidney transplant within 36 months after a transplant.

Note: If your child is age 18 or older and is getting disability benefits from Social Security, their Medicare coverage may continue based on his or her disability.

Dialysis and Kidney Transplant Services and Supplies Covered by Medicare

Covered dialysis services and supplies

Medicare covers and helps pay for some dialysis services such as

- inpatient and outpatient dialysis treatments,
- dialysis training,
- home dialysis equipment and supplies,
- certain home support services (might include visits by trained hospital or dialysis facility workers to check on your child's home dialysis, to help in emergencies when needed, and to check dialysis equipment and water supply),
- certain drugs for home dialysis including topical anesthetics, erythropoietin, Heparin, and the antidote for Heparin when medically necessary,
- outpatient doctors' services, and
- most other services and supplies that are part of dialysis, like laboratory tests.

What Medicare doesn't cover

Examples of dialysis services and supplies that Medicare doesn't cover include

- paid dialysis aides to help with home dialysis,
- any lost pay to you or your spouse during home dialysis training,
- a place to stay during treatment,
- blood or packed red blood cells for home dialysis unless part of a doctor's service or if needed to prime the dialysis equipment, and
- transportation to the dialysis facility.

Dialysis and Kidney Transplant Services and Supplies Covered by Medicare (continued)

Covered kidney transplant services

Medicare covers and helps pay for some transplant services such as

- inpatient hospital services in an approved hospital,
- laboratory and other tests needed to evaluate your child's medical condition,*
- laboratory and other tests needed to evaluate the medical conditions of potential kidney donors,*
- the costs of finding the proper kidney for your child's transplant surgery (if there is no kidney donor),
- the cost of care for the kidney donor related to kidney donation,
- any additional inpatient or outpatient hospital care for the donor in case of problems due to surgery,
- doctors' services for kidney transplant surgery,
- doctors' services for the kidney donor during their hospital stay,
- immunosuppressive drugs following a transplant paid for by Medicare, or paid by a private insurance that paid primary to Medicare, and
- blood.

* These services are covered whether they are done by the Medicare-approved hospital where your child will get a transplant, or by another hospital that participates in Medicare.

Medicare and Other Health Insurance

How Medicare works with other health insurance

It's important that you tell doctors and hospitals that your child has Medicare and another insurance, so bills are handled correctly.

If your child is included on your employer group health plan or private insurance policy, this insurance will be the primary payer on your child's hospital and medical bills for the first 30 months your child is eligible for Medicare because of End-Stage Renal Disease. Medicare will be the secondary payer during this period. This 30 month period is called the "coordination period."

At the end of the 30-month coordination period, Medicare will become the primary payer and will pay first for all Medicare-covered services. Your private or employer group health plan will become the secondary payer and may pay for services Medicare doesn't cover. Check with your plan's benefits administrator for more information.

When the 30-month coordination period starts

Words in red are defined on pages 18–19.

In most cases, the 30-month coordination period starts the first month your child is able to get Medicare because of End-Stage Renal Disease (usually the fourth month of dialysis), even if you haven't signed up for Medicare yet. However, if your child starts home peritoneal dialysis or home hemodialysis during the three-month waiting period (see page 6) or gets a kidney transplant (see page 7), the 30-month coordination period will start with the first month of dialysis or the month he or she had the kidney transplant. If your child is admitted to a hospital prior to the transplant, the coordination period will begin two months before the transplant.

Medicare doesn't cover any services during the three-month qualifying (or waiting) period. Your employer group health plan or private insurance policy will be the only payer during the first three months of treatment.

At the end of the 30-month coordination period, Medicare will pay first for all Medicare-covered services. Your private or employer group health plan coverage may pay for services that Medicare doesn't cover. Check with your plan's benefits administrator for more information.

Other Ways to Pay Health Care Costs

In addition to Medicare, you might be able to get additional help to cover your child's health care costs. A member from your child's health care team can help you find out more about the programs listed below.

State programs

Medicare Savings Programs—State Medicare Savings Programs help millions of people with Medicare save money each year. These programs might help people with limited resources pay out-of-pocket Medicare costs like premiums, deductibles, and coinsurance. You must meet your State's income limits to apply. Call your State Medical Assistance Office for more information and to find out if you qualify.

Medicaid—If your income and resources are limited, your child may qualify for Medicaid. Most health care costs are covered with both Medicare and Medicaid. Medicaid is a joint Federal and State program that helps pay medical costs for some people with limited incomes and resources. Medicaid programs vary from state to state. People with Medicaid may get coverage for things like nursing home care, home care, and outpatient prescription drugs that aren't covered by Medicare. For more information about Medicaid, call your State Medical Assistance Office.

Words in red are defined on pages 18–19.

State Children's Health Insurance Program (SCHIP)—Free or low-cost health insurance is available now in your State for uninsured children under age 19. State Children's Health Insurance Programs help reach low-income, uninsured children whose families don't qualify for Medicaid. Information on your State's program is available through Insure Kids Now at 1-877-KIDS-NOW (1-877-543-7669). You can also look at www.insurekidsnow.gov on the web for more information.

Note: If you enroll your child in Medicaid or a State Children's Health Insurance Program (SCHIP), your State may require you to enroll your child in Medicare in order to get Medicaid or qualify for SCHIP.

Other Ways to Pay Health Care Costs (continued)

Kidney Disease Programs—Some States have kidney disease programs that offer health care to children with End-Stage Renal Disease. To find out if your State has a kidney disease program, contact your Department of Social Services. You can find their telephone number in your local telephone book.

Where to Go for More Information

About Medicare and how to enroll

Look at www.medicare.gov on the web.

- Select "Publications" for free Medicare booklets such as *Enrolling in Medicare* (CMS Pub. No. 11036) and the *Medicare & You* handbook (CMS Pub. No. 10050).
- Select "Medicare Eligibility Tool" for information about Medicare eligibility and enrollment.
- Select "Your Medicare Coverage" for information about Medicare supplies and services that are covered in the Original Medicare Plan.

Or, call 1-800-MEDICARE (1-800-633-4227). TTY users should call 1-877-486-2048.

Where to Go for More Information (continued)

About kidney disease

American Association of Kidney Patients

www.aakp.org

Visit this website to read brochures and newsletters about kidney disease and treatments, and other related issues such as diet. You can also find information on advocacy, locate a local chapter in your area, and get information on special programs and events.

American Kidney Fund

www.akfinc.org

Visit this website to learn kidney disease facts and figures. Find out about American Kidney Fund programs including discount pharmacy cards and other medication programs, grants, minority outreach, educational materials, a helpline, and disaster relief for patients.

Children's Organ Transplant Association, Inc.

www.cota.org

If you have a child who needs a kidney or other organ transplant, the Children's Organ Transplant Association (COTA) can give you financial and fundraising help. This site also has newsletters, real-life patient stories, and an annual report you can download.

National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC)

www.kidney.niddk.nih.gov

This website is a service of the National Institute of Health. Click on the list of topics and select "Children" to find information for parents of children with kidney disease. On this site you can find an overview of kidney disease in children, treatment options, and managing growth, family, and school issues.

Where to Go for More Information (continued)

National Kidney Foundation (NKF)

www.kidney.org

Type "kids" or "children" into the search box on this website. You will find a glossary, camp lists, frequently asked questions for parents on topics like bedwetting and nutrition, a kidney cookbook for children, and information about children in the yearly transplant games.

Renal Support Network

www.renalnetwork.org

This website has information for people with kidney disease and their family members. It includes a renal library with articles about medical and lifestyle issues. You can also find information about advocacy and get links to more kidney disease resources.

Starbright Foundation

www.starbright.org

This organization develops materials to help children and teenagers deal with the medical and emotional challenges of having a chronic health condition. Visit this website to get a free copy of an interactive CD-ROM "Living with Kidney Disease." The CD-ROM is for children from ages 10–12 and includes topics like how kidneys work and what to expect from treatment.

Where to Go for More Information (continued)

About how to find a dialysis facility

In most cases, your child will get dialysis at the facility where his or her doctor works. However, you have the right to choose the facility where your child gets treatments at any time. Changing facilities might mean you will have to change your child's doctor too.

You can call your local End-Stage Renal Disease Network to help you find a facility that is close to you. To find the End-Stage Renal Disease Network in your state go to www.esrdnetworks.org on the web.

"Dialysis Facility Compare" on the web

The Dialysis Facility Compare website has important information about Medicare-certified dialysis facilities in your area and across the country. Look at www.medicare.gov on the web. Select "Dialysis Facility Compare." You can find information such as facility addresses and telephone numbers, how far certain facilities are from you, and what kind of dialysis services the facilities offer. You can also compare facilities by the services they offer and by certain quality of care information. Helpful websites, publications, and telephone numbers are also available. You can discuss the information on this website with your child's health care team.

Words in red are defined on pages 18–19.

Words to Know

Coinsurance—The percent of the Medicare-approved amount that you have to pay after you pay the deductible for Part A and/or Part B. In the Original Medicare Plan, the coinsurance payment is a percentage of the approved amount for the service (like 20%).

Deductible—The amount you must pay for health care before Medicare begins to pay, either for each benefit period for Part A, or each year for Part B. These amounts can change every year.

End-Stage Renal Disease—Kidney failure that is severe enough to require lifetime dialysis or a kidney transplant.

End-Stage Renal Disease Network—Non-profit organizations paid by Medicare. They assist dialysis facilities with improving patient care. The ESRD Networks can help you with questions you may have about dialysis facilities, and help you if you have a complaint about a dialysis facility.

Hemodialysis—A type of treatment that uses a special filter (called a dialyzer) to clean your blood. The filter connects to a machine. During treatment, your blood flows through tubes into the filter to clean out wastes and extra fluids. Then the newly cleaned blood flows through another set of tubes and back into the body.

Immunosuppressive Drugs—Transplant drugs used to reduce the risk of rejecting the new kidney after the transplant. Transplant patients will need to take these drugs for the rest of their lives.

Medicare Part A (Hospital Insurance)—Hospital insurance that pays for inpatient hospital stays, care in a skilled nursing facility, hospice care and some home health care.

Medicare Part B (Medical Insurance)—Medical insurance that helps pay for doctors' services, outpatient hospital care, and other medical services that are not covered by Part A.

Words to Know (continued)

Peritoneal dialysis—A type of treatment that uses a cleaning solution, called dialysate, that flows through a special tube into the abdomen. After a few hours, the dialysate gets drained from the abdomen, taking the wastes from the blood with it. Then the abdomen gets filled with fresh dialysate and the cleaning process begins again.

Premium—The periodic payment to Medicare, an insurance company, or a health care plan for health care coverage.

Important Telephone Numbers

1-800-MEDICARE (1-800-633-4227)

Doctor(s)

Social Worker

Dialysis Facility

Health Insurance Company

ESRD Network

Notes

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